

# Cancer Survivorship in Australia

A review of Australia's cancer survivorship landscape and opportunities to improve care and support for all cancer survivors



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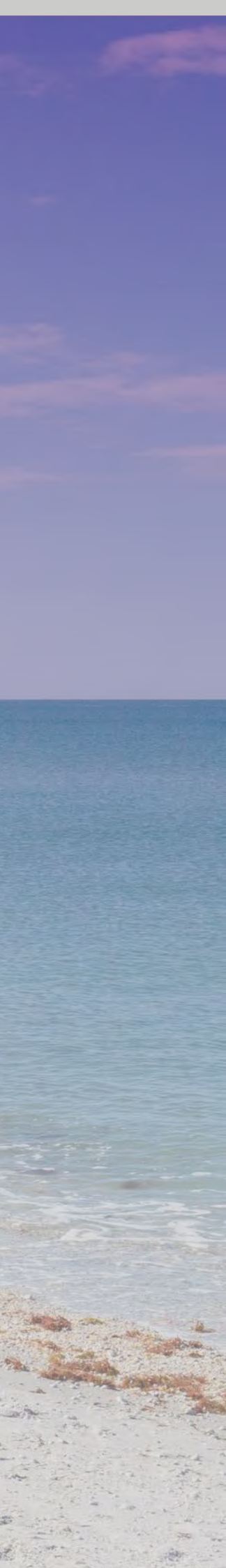
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# Table of contents

|                                                                                         |           |
|-----------------------------------------------------------------------------------------|-----------|
| <b>Executive Summary</b>                                                                | <b>2</b>  |
| <b>1. Cancer Survivorship</b>                                                           | <b>5</b>  |
| 1.1 The needs of survivors                                                              | 6         |
| 1.2 A new era of survivorship                                                           | 6         |
| <b>2. Existing models of survivorship care</b>                                          | <b>7</b>  |
| 2.1 Gaps in survivorship care                                                           | 8         |
| <b>3. Access to information and services</b>                                            | <b>11</b> |
| 3.1 Availability of best practice services                                              | 11        |
| 3.2 Awareness of and referral to services                                               | 13        |
| 3.3 Integration of services                                                             | 13        |
| 3.4 Social acceptability of accessing services                                          | 14        |
| <b>4. Costs of services and other out of pocket costs</b>                               | <b>14</b> |
| <b>5. Challenges for patients in rural locations and vulnerable groups of survivors</b> | <b>16</b> |
| 5.1 Access to services                                                                  | 16        |
| 5.2 Suitability of available survivorship support                                       | 18        |
| 5.3 Lack of health literacy                                                             | 18        |
| <b>6. Key gaps in the Australian survivorship landscape</b>                             | <b>19</b> |
| <b>7. Innovative models of survivorship care</b>                                        | <b>20</b> |
| 7.1 Virtual models of care                                                              | 20        |
| 7.2 Appropriate funding mechanisms                                                      | 22        |
| <b>8. Recommendations</b>                                                               | <b>23</b> |
| <b>9. Conclusions</b>                                                                   | <b>25</b> |
| <b>10. Appendix</b>                                                                     | <b>27</b> |
| 10.1 Existing frameworks and models of survivorship care                                | 27        |
| 10.2 Australian survivorship services                                                   | 30        |
| 10.3 Abbreviations                                                                      | 31        |
| <b>11. References</b>                                                                   | <b>32</b> |



# Executive Summary

Over the past few decades, many cancers that used to be fatal have become curable or amenable to long-term control. As a result, an increasing number of people are living beyond the cessation of acute treatment. These people may view themselves as cancer “survivors” while others may prefer to be identified as “a person who has had cancer” or as someone “living with cancer” (1). While these people might no longer view themselves as “patients”, many have ongoing needs for individualised and culturally sensitive physical and psychosocial support.

Bristol Myers Squibb (BMS) Australia is a leader in the development and provision of innovative cancer therapies, which are contributing significantly to improved outcomes for cancer patients. This includes the development of novel immunotherapies, which have transformed the treatment paradigm for some cancers, such as melanoma and lung cancer. As these novel therapies shape the way cancer is treated, there is a need to consider the experiences and needs of both cancer patients and survivors – including those for which cancer may be considered a chronic disease.

Further consideration of cancer survivorship is also timely given the new Australian Cancer Plan (ACP) currently being developed by Cancer Australia. The ACP will outline key national priorities and actions to be undertaken over the next 10 years in order to improve health outcomes for Australians impacted by cancer (2).

Part of BMS’s role in addressing cancer is to anticipate the challenges associated with their therapies and assist the Australian health sector in addressing them. BMS is, therefore, committed to exploring opportunities that will help drive improvements in Australian cancer survivorship care.

These improvements need to be informed by evidence, which led BMS to commission Biointelect to answer three questions:

1. What programs and services are available to cancer survivors in Australia?
2. What are the most significant challenges faced by survivors?
3. What are the most significant gaps in existing survivorship services and what steps might be taken to address them?



Biointellect answered these questions using a mixed methods approach comprising desk research, a survey of patient advocacy organisations, and interviews with key stakeholders.

The research revealed that, while there are well-defined models for cancer survivorship (both internationally and in Australia), the provision of survivorship care in Australia is highly fragmented. There is also considerable variation between institutions and across jurisdictions, with many services concentrated within metropolitan cities. This inconsistent approach to survivorship care is driving a number of notable gaps and challenges including:

- > lack of access to information and services,
- > costs of services and other out-of-pocket costs,
- > challenges for vulnerable patient groups.



What's more, as innovations in cancer diagnosis, screening and treatment continue to emerge, the number of people living with a personal history of cancer is expected to continue to increase in coming years. Existing models of survivorship care are highly resource intensive and already failing to effectively meet the needs of many survivors. Consequently, the long-term sustainability of survivorship care is an ongoing issue that warrants careful consideration.

This White Paper explores the gaps and challenges throughout the Australian survivorship landscape and makes recommendations for addressing them. Its key recommendations are:



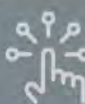
1. Undertake policy reform to ensure a consistent, nationwide approach to cancer survivorship



2. Develop innovative models of survivorship care that not only address existing gaps within the Australian survivorship landscape but will also remain sustainable long term in the face of increasing numbers of cancer



3. Consider alternative models of funding for survivorship care that help drive the provision of high-quality survivorship care.



4. Strengthen Australia's telehealth and digital health infrastructure to ensure these can be utilised to their full potential.



# 1. Cancer Survivorship

Cancer is a common, disabling and often life-threatening condition. In 2018 an estimated 140,000 new cases of cancer were diagnosed in Australia with 47,000 deaths (3). In 2011, cancer was the greatest cause of disease burden in Australia— accounting for 19% of the total disease burden. This was greater than the burdens of cardiovascular diseases and mental and substance use disorders (4). Population growth and an aging population suggest that the burden of disease will continue to increase into the future (5).

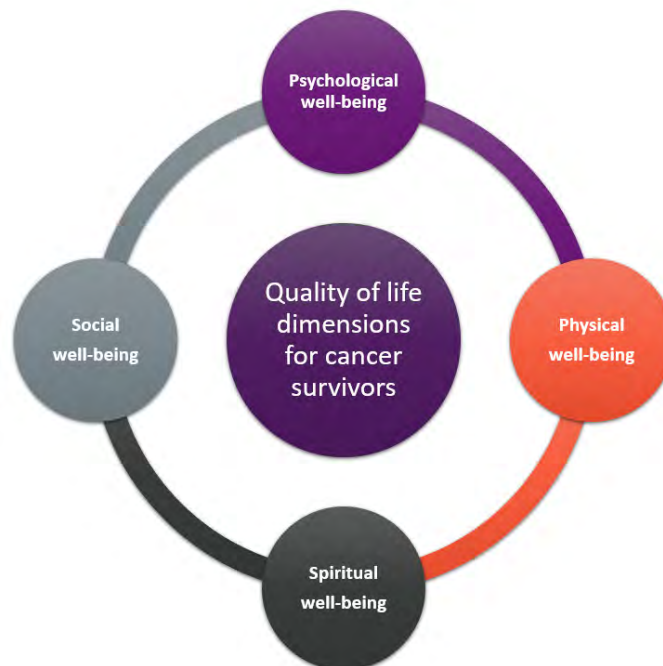
Over the past few decades, many cancers that used to be fatal have become curable or amenable to long-term control. The 5-year relative survival rate for all cancers in Australia increased from 50% in 1986–1990 to 69% in 2011–2015 (5). This increase in survival has been a result of both earlier detection and intervention, and advances in surgical and medical treatment options. An estimated 40% of progress can be attributed to innovative cancer medicines including targeted therapies and immunotherapies such as checkpoint inhibitors (CPIs) and chimeric antigen receptor T-cell (CAR T-cell) therapies (6).

With more people living longer after a cancer diagnosis, the number of patients who have either “survived” cancer or live with it as an actively managed chronic condition has increased markedly. In 2018, 1.1 million Australians were reported to have a personal history of cancer, and this number is projected to increase to 1.9 million people by 2040 (7).

## 1.1 The needs of survivors

The needs of these survivors are complex and highly individual. Some return to life as “normal” but others remain at risk of developing long term health issues including organ dysfunction and secondary malignancies, cardiovascular disease, type 2 diabetes, metabolic syndrome and osteoporosis (7).

For many people, these physical issues are compounded by financial, psychological, social and spiritual challenges (8). For example, many survivors live with fear of cancer recurrence and patients frequently experience distress as a result of changes in social roles, intimate relationships and ability to work (8). It is, therefore, important that the needs of survivors be viewed holistically – taking into account both the direct, physical impacts of treatment and disease sequelae, and broader dimensions of quality of life (8).



8. Incorporating a Survivorship Clinic into Practice. Economou D. 343-346, s.l. : Journal of the Advanced Practitioner in Oncology, 2016, Vol. 7(3).

In August 2020, Biointelect was commissioned by BMS to conduct an online survey of relevant Australian patient advocacy organisations to better understand the experiences of Australian cancer survivors. These results suggested that the most common physical concerns of cancer survivors are fatigue, lymphedema, joint pain, weight loss, breathlessness and prolonged cough (for lung cancer patients). Also reported was considerable anxiety about recurrence, and challenges associated with the transition away from acute care with loss of healthcare practitioner support.

Importantly, the concerns of cancer survivors vary according to their age, life stage and disease—for example body image is a concern primarily for younger patients, while people of childbearing age have the greatest concerns about fertility and the potential of passing on their condition.

Concerns are also often specific to the type of treatment being received. For example, patients receiving long term immunotherapy may be concerned about the variability and unpredictability of side effects of immunotherapies compared with (more familiar) standard chemotherapy, and about specific long-term adverse effects such as development of Type 1 diabetes, hypothyroidism and adrenal dysfunction (9) (10).

## 1.2 A new era of survivorship

As outlined above, the past few decades have seen significant developments in the diagnosis and management of cancer. The evolution of precision medicine and genomics has revolutionized the clinical management of



various cancer types. For example, molecular profiling is now an important consideration in the treatment and management of non-small cell lung cancer (NSCLC) – creating an opportunity for the utilization of targeted therapies and a personalized treatment approach (11). Those who respond to targeted therapies are now typically expected to survive 3-4 years post diagnosis, as compared to surviving only months without them (12). Tyrosine kinase inhibitors (TKIs) such as imatinib have revolutionised the treatment of chronic myeloid leukaemia (CML) (13), increasing the 5-year survival rate from 22% in the 1970s to 72% today (14), and transforming CML into a chronic condition for many patients (15). Combinations of drugs targeting other kinases (e.g. HER-2) and hormone receptors have significantly increased survival from some types of breast cancer (16).

Innovative medicines such as immunotherapies and CAR-T cell therapies have significantly increased the survival rates for certain cancer types by utilising a patient's own immune system to fight the cancer (17). For example, in malignant melanoma, 5-year survival rates have increased from 7% to 63% with a combination of ipilimumab and nivolumab (18), which work by inhibiting the cytotoxic T-lymphocyte-associated antigen 4 (CTLA-4) and programmed death 1 (PD-1) immune checkpoints respectively (19).

As these novel diagnostic tools and therapies continue to evolve, a new form of cancer patient and survivor is emerging. Importantly, the experiences, needs and expectations of these cancer survivors may differ to those of survivors who have been treated with older treatment options like cytotoxic chemotherapy. For example, one study of 20 NSCLC survivors found that NSCLC patients treated with novel immunotherapies or targeted therapies may specifically benefit from information around the long-term toxicities of their treatment as well as psychological support (20). The issue of long-term toxicity is particularly notable considering the impact these novel therapies have had on survival rates, their potential ongoing use and the fact that they have not been available long enough to fully understand the long-term impact on survivors. As a result, it's important to consider how the needs of these patients and survivors may differ compared to those who have received more established treatment modalities.

## 2. Existing models of survivorship care

A number of survivorship “models of care” have been developed, locally and internationally as outlined in the Appendix. These have largely been based on the landmark 2006 report *From Cancer Patient to Cancer Survivors: Lost in Transition*, which sought to highlight the unique needs and challenges faced by survivors.

Several Australian frameworks have been developed, which articulate broad principles and strategies for survivorship care and support, including Cancer Australia's Principles of Cancer Survivorship and the Clinical Oncology Society of Australia's (COSA) Model of Survivorship Care (21) (see Appendix).

There are a number of institutions in Australia that provide some form of survivorship care or support (22). Services that are provided include:

- Support groups, including peer to peer support
- Helpline support and nurse / tele-nurse support services
- Psychosocial services, including referral of patients to appropriate services
- Provision of information and education for patients, carers and healthcare professionals
- Access to gyms and nutrition programs

Digital tools to facilitate survivorship care are currently in being investigated and developed (23). An example of this is the development of an online survivorship platform for brain cancer survivors and carers, which aims to streamline access to treatment teams and peer support, while also providing evidence based supportive care (24).

Cancer Australia is also in the process of developing an Australian Cancer Plan which will outline key priorities and actions over the next 10 years required to improve outcomes for Australians affected by cancer. The Australian Cancer Plan is intended to cover the full continuum of cancer care, including survivorship (2).

## 2.1 Gaps in survivorship care

In 2006, the Institute of Medicine (IOM) identified a number of gaps in survivorship care, and its *Lost in Transition* report included 10 recommendations for improvement (25):

- Raising awareness of survivor needs
- Survivorship Care Plan provided for patients completing primary treatment
- Utilising evidence-based guidelines and tools to manage the late effects of treatment
- Developing and implementing quality measures to improve care that survivors receive
- Models of coordinated care to provide interdisciplinary survivorship care
- Survivorship as a public health concern alongside comprehensive cancer control plans
- Healthcare professional capacity expansion
- Employment-related concerns and discrimination should be addressed
- Adequate and affordable health insurance including recognising survivorship care as an essential component of cancer care
- Investment in research in the survivorship space

Unfortunately, many of these gaps in survivorship care are reported to persist today (26) (27) (28) (7):

### **Lack of cancer rehabilitation programs**

- Cancer rehabilitation is typically delivered by a multidisciplinary rehabilitation team comprising clinicians and other allied health professionals. Programs are designed to assist patients in returning to normal living.
- There are currently minimal cancer rehabilitation services available to Australian patients. As a result, patients may be directed to programs which aren't designed for cancer survivors, such as stroke rehabilitation programs.

### **Lack of consideration of specific cancer types and individual needs**

- Cancer is a diverse set of diseases with varying treatments and toxicities. Failing to take this into consideration in developing survivorship care can result in care gaps or ineffective interventions.
- Most resources are oriented to common cancers and not to rare cancers or rare subsets of more common cancers.
- There is far more knowledge of, and attention paid, to the needs of patients receiving standard chemotherapies than to newer therapies such as immunotherapies.
- Even with common cancers, different groups of patients have different needs and priorities (e.g., access to pulmonary rehabilitation for lung cancer patients, access to family support for teenagers and access to genetic counselling for patients of child-bearing age) and these differences are not always accommodated.

### **Lack of holistic care**

- Overall, existing survivorship programs are fragmented with few holistic models in place that take into account all aspects of survivorship.

### **Lack of evidence-based services**

- Existing models of care have not been sufficiently evaluated for effectiveness and ongoing evaluation is not built into the models.
- Survivorship interventions are rarely evaluated for cost-effectiveness from the perspective of providers or the healthcare system.

### **Inadequate resourcing of services (and associated workforce)**

- Some healthcare practitioners have reported a lack of resources for the effective implementation of survivorship interventions.
- A lack of reimbursement may provide a barrier to uptake with aspects of survivorship care considered “non-revenue generating” services.
- Particular types of services (e.g., nurse navigator supports) are perceived to be particularly in need of greater funding.

### **Lack of survivor consultation**

- A lack of input from survivors themselves into the design and delivery of services can result in poorly targeted interventions.

### **Inequitable access to services**

- It is well recognised that location and socioeconomic status contribute to cancer outcomes, with rural and remote patients having less access to services and being more likely to experience comorbidities and poor health outcomes.
- There is also significant variation in available services among the states.

### **Lack of referral to services**

- The current uptake of and referral to survivorship support by specialists and GPs is insufficient.

### **Out of pocket costs and financial toxicity**

- Key concerns include lack of reimbursement for ongoing disease surveillance and the ongoing need for pharmaceuticals not listed on the Pharmaceutical Benefits Scheme (PBS).
- Cost / financial toxicity may be compounded if maintenance therapy is required.

### **Lack of awareness of survivorship and survivorship services**

- Other gaps are all likely caused or exacerbated by lack of awareness of survivorship services amongst both patients and healthcare professionals and lack of training of healthcare professionals regarding survivorship care.

## **Key gaps and challenges**

Many of the above gaps and challenges can be synthesised into three key intersecting areas of concern:

- › Access to information and services
- › Costs of services and other out-of-pocket costs
- › Challenges for vulnerable groups of survivors, such as culturally and linguistically diverse populations, or those living outside metropolitan centres

These have been explored within the Australian context in sections 3-6.



## 3. Access to information and services

A key component of survivorship care is ensuring that patients have access to the right type of care from the right provider(s) at the right time. However, a recent survey of Australian healthcare professionals and representatives from healthcare organisations identified as providing dedicated cancer services, found that access to survivorship care appears to be the largest service gap that they experience (29). This is substantially larger than the next gap—provision of general oncology services.

**Figure 1: Key gaps in cancer services as identified by Hunter J. et al.**

|                                           | Major Cities <sup>a</sup> |       | Regional |                  | Remote |                  | Total |                       |
|-------------------------------------------|---------------------------|-------|----------|------------------|--------|------------------|-------|-----------------------|
|                                           | n                         | %     | n        | %<br>OR (95% CI) | n      | %<br>OR (95% CI) | n     | %<br>(95% CI)         |
| Survivorship/Supportive Care <sup>a</sup> | 41                        | 61.2% | 30       | 50.0%            | 29     | 39.2%            | 100   | 49.6%                 |
| Weighted count <sup>b</sup>               | 33                        | 56.9% | 33       | 51.6%            | 30     | 38.7%            | 95    | 47.9%<br>(43.6–57.4%) |
| Specialist Oncology Services              | 4                         | 6.0%  | 9        | 15.0%            | 21     | 28.4%            | 33    | 16.4%                 |
| Weighted count <sup>b</sup>               | 2                         | 3.4%  | 7        | 10.9%            | 22     | 28.8%            | 32    | 16.1%<br>(11.9–22.2%) |
|                                           |                           |       | 2.67     | (0.74–9.65)      | 6.16** | (1.87–20.23)     |       |                       |
| Palliative Care/Hospice                   | 9                         | 13.4% | 15       | 25.0%            | 9      | 12.2%            | 33    | 16.4%                 |
| Weighted count <sup>b</sup>               | 9                         | 15.5% | 15       | 23.4%            | 10     | 13.0%            | 33    | 16.7%<br>(11.9–22.2%) |
|                                           |                           |       | 2.18     | (0.82–5.09)      | 1.40   | (0.48–4.07)      |       |                       |
| General Cancer Service Resources          | 10                        | 14.9% | 6        | 10.0%            | 15     | 20.3%            | 32    | 15.9%                 |
| Weighted count <sup>b</sup>               | 14                        | 24.1% | 9        | 14.1%            | 15     | 19.5%            | 38    | 19.4%<br>(11.5–21.6%) |
|                                           |                           |       | 0.80     | (0.26–2.50)      | 1.98   | (0.76–5.20)      |       |                       |
| Total                                     | 67                        | 100%  | 60       | 100%             | 74     | 100%             | 201   | 100%                  |

\*\* $p = 0.003$ ; <sup>a</sup> reference categories for multinomial logistic regression of service gaps (excluding none) and remoteness (major cities, rural, remote), [19] after adjusting for respondent's role and cancer service ownership; <sup>b</sup> count weighted by number of respondents per Primary Health Network region: missing responses  $n = 77$

29. Coverage of cancer services in Australia and providers' views on service gaps: findings from a national cross-sectional survey. Hunter J. et al. : BMC Cancer, 2019, Vol. 19:570.

### 3.1 Availability of best practice services

The availability of survivorship services is highly variable across Australia, with most concentrated in or around capital cities (29). Even in capital cities, the financial resources that are currently allocated to cancer care are increasingly being stretched as patients live longer and develop new needs associated with survivorship. According to an Australian medical oncology workforce survey, increased duration of survival has contributed to more complex care and higher patient loads (30). The realities of this experience were articulated by a nurse interviewed for this project:

*“In reality, 95% of my day is taken up dealing with people who are acutely unwell ... there are not many hours left anywhere. I see patients on pressing issues and more present time focus.... (I) don't have capacity to support all survivors who don't have acute needs.” (Oncology nurse)*

Resource limitations are exacerbated by limits in the number of healthcare professionals who have the training necessary to provide the specialised care that survivors need. Increasing demands on cancer services have also been accompanied by workforce trends such as tumour-based subspecialisation and changes to career entry and exit points (30). While all types of healthcare professionals are in short supply, healthcare advocacy organisations have highlighted the shortage of specialised cancer nurses and nurse navigators. This shortage, it is argued, compromises the delivery of best practice care because these nurses not only support patients and their families but also reduce unnecessary admissions to emergency departments and support medical and surgical oncologists (31) (32).

In some cases, these funding and workforce limitations mean that patients cannot access survivorship services at all. But even where patients can access services, it is likely that they will not meet all the needs of all the patients who access them. Available resources are distributed unequally across cancer types—with some cancers, such as breast cancer, receiving what is perceived to be a disproportionate amount of funding. As one participant observed:

*“The thing that always strikes me is that breast cancer is something that is very well supported [with] high visibility. [There are] a lot of other cancers that we don't see [and a] perception that other cancers aren't as important as visible ones. Anyone that has a cancer diagnosis would benefit from support.” (Cancer Services Provider, NSW Health)*

These kinds of disparities have been demonstrated empirically. For example, a review of cancer research funding in Australia conducted by Cancer Australia demonstrated the disparity between the funding provided for breast cancer between 2016 and 2018 compared with other tumours. This disparity is particularly notable when one considers the burden of disease associated with breast cancer compared with prostate and lung cancers (33). Similarly, the Lung Foundation Australia's Lung Cancer Scorecard illustrates the disparity between research investment and disease burden associated with breast compared with lung cancer (34).

Available services are also not always fit for purpose for specific patients. For example, current assessment tools used in oncology, such as “distress thermometers” and “problem checklists,” might be more suited to use in the acute phases of treatment than in the survivorship phase (35) (36). It is also increasingly recognised that tools need to accommodate differences among diseases and among the social and psychological needs of individual patients.

This lack of resourcing and lack of tailored services not only impacts upon patients (who cannot access the care they need) but also creates dissatisfaction among staff, who might feel that theories and policy decisions

regarding optimal survivorship care are developed without taking into account the practicalities of delivering on that care.

*“Sometimes gold standard or theoretical survivorship ideas [are not] practical in reality.” (oncology nurse)*

## 3.2 Awareness of and referral to services

Even where survivorship services exist and are adequately resourced, they might not be accessed simply because patients do not know about them, or healthcare professionals fail to alert and refer patients to them. As one medical oncologist observed:

*“A lot of people don’t understand the role and importance of patient advocacy groups and non-government groups. They don’t understand organisations are not just someone making something up in their back yard. What they produce is very high quality, services are valuable and well developed.” (medical oncologist)*

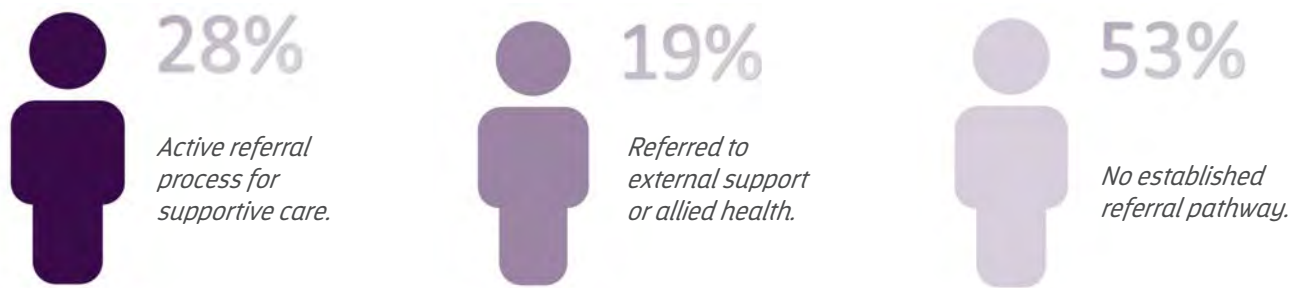
In a study of patients with brain cancer, awareness of and referral to services was highly variable—for example 77% of participants were referred to, and 60% used, physiotherapists. In contrast, none reported being referred to an advocacy organisation, or to exercise physiologists, psychiatrists, financial counsellors or advisors, or a wig and turban service. Importantly, many patients stated that they would have wanted to access services had they been made aware of them (37).

Some survivors are alert to these problems, and report difficulties in accessing information, finding people with whom to discuss their options for support and care, and accessing appropriate referral pathways to survivorship care (38). It is important to bear in mind, however, that not all patients have sufficient health literacy to recognise for themselves that there are gaps in their care and either seek out services themselves or advocate for referral.

## 3.3 Integration of services

Ideally, assessment of survivor needs and appropriate referral should occur at diagnosis and then at every transition point along the patient’s trajectory (e.g. treatment change, treatment completion, transition, recurrence, referral to palliative care). In reality, however, the process of referring patients to appropriate survivorship services is made difficult by the lack of integration of survivorship services into existing care pathways.

A national survey mapping supportive cancer care referral pathways and service provision in 124 hospitals with cancer services found that only 28% provided cancer-specific supportive care service or direct access to services via an affiliated cancer centre, 53% had no established referral pathway, and only 19% referred survivors (on an ad-hoc basis) to external organisations or allied health professionals (29) (39).



39. Integration of complementary and alternative medicine into cancer-specific supportive care programs in Australia: A scoping study. Lim E; et al. s.l. : Asia-Pacific Journal of Clinical Oncology, 2017, Vol. 13.

Lack of information about, integration of and referral to psychological support services is an issue of particular concern. Indeed, even groups of patients with high reported psychological needs, such as survivors of brain tumours (37), report problems accessing such services.

### 3.4 Social acceptability of accessing services

A key theme that emerges in discussions with cancer survivors and other stakeholders is that survivorship and associated needs are poorly understood by the general public. While the active treatment and/or palliative care phases of the cancer journey are thoroughly (and generally sympathetically) represented in the media, the same is not true for cancer survival. Families and friends of survivors, and even healthcare professionals might also fail to recognise the ongoing needs of survivors, and express frustration that they are not returning to “normal.” (40). In addition to creating the sense among cancer survivors of being overlooked or forgotten, this lack of representation and recognition might prevent cancer survivors from viewing themselves as having legitimate needs and discourage them from accessing services. It might also limit the degree to which survivors feel willing or able to advocate for more comprehensive service provision.

At the same time, not all cancer survivors want to be identified as such, and many have a desire to return to (some version of) “normal” life, so some might experience the “opposite” problem—being viewed as having service needs that they do not perceive themselves as having.

## 4. Costs of services and other out of pocket costs

Many cancer survivors experience financial instability, or “toxicity,” because of the costs of ongoing (maintenance) cancer treatments, ongoing surveillance for disease recurrence, and therapies required to treat co-morbidities and the long-term sequelae of their disease or treatments (41). These financial challenges are compounded by the

fact that survivors may not be able to return to the same level of work as before their illness, yet are simultaneously now living longer than ever. As such, for many patients cancer can be considered a chronic health condition, which causes at least as much, if not more, financial distress than do other chronic health conditions (42).

A review of the literature reveals that the out-of-pocket costs associated with imaging are particularly problematic for survivors. There is variation in public insurance (Medical Benefits Schedule) coverage of imaging, with limitations in funding for even common cancers unless specific criteria are met (e.g., MRIs for some survivors of breast cancer and prostate cancer). In a survey conducted by the Consumers Health Forum of Australia (CHF), patients expressed most concern about the out-of-pocket costs associated with diagnostic scans that are not subsidised via the MBS (43).

Non-medical expenses, such as hospital car parking, also add significantly to cancer survivors' financial burdens. These expenses are exacerbated by the difficulties that some cancer survivors have in remaining employed (44).

Female survivors, younger survivors, those with low incomes and those receiving adjuvant therapies (i.e., therapies used to enhance the effectiveness of the primary modality) are most likely to experience financial toxicity (42). Cancer survivors living in rural and remote areas have additional costs associated with travel to metropolitan centres for ongoing treatment and surveillance (40).

There is evidence that private health insurance coverage is also an important predictor of out-of-pocket costs for cancer patients. A so called "insurance misalignment" may contribute to these out-of-pocket costs, whereby patients are directed to private services due to their insurance, but consideration is not given to their policy coverage (42). Furthermore, it has been reported that additional tests may be recommended for patients with private coverage (42). These additional costs may impact patients throughout both their treatment and ongoing survivorship and are particularly important to consider in light of the fact that private health coverage does not necessarily correlate with higher income (42).

Lack of transparency regarding costs is a major issue for cancer survivors. The CHF survey revealed that patients are often not aware that they could face significant out of pocket costs or that they have the right to "shop around" for more affordable services (43). Cancer survivors are also often unaware of social services available to Australian citizens and permanent residents. Stakeholders therefore emphasise the importance of healthcare professionals both being transparent about the costs of their services and helping patients to navigate the system in cost-efficient way (38).

The financial difficulties experienced by cancer patients are exacerbated for patients living in rural areas, who have to pay for travel and associated costs such as missing work, leaving businesses unattended and needing to find and pay for child-care (40). These costs might also extend to carers who need to accompany patients to urban areas. The additional financial toxicity experienced by rural survivors was confirmed in a recent systematic review, which found that rurality is a key factor associated with financial toxicity for cancer patients (45).



Importantly, the impacts of financial toxicity are not simply economic, as patients with serious financial concerns might forego ongoing treatment or scans. Financial distress has, therefore, been identified as a risk factor for mortality among cancer patients (38).

## 5. Challenges for patients in rural locations and vulnerable groups of survivors

It is well recognised that certain “vulnerable” groups of people with cancer typically face poorer health outcomes than the average Australian. For example, Aboriginal and Torres Strait Islander people are approximately 40% more likely to die from cancer than non-Indigenous Australians (46) while inequity across the cancer continuum has been identified amongst those of culturally and linguistically diverse (CALD) backgrounds (47). Australian cancer patients from remote or very remote areas are 35% more likely to die within 5 years of a cancer diagnosis than those living in metropolitan areas (48). These disparities typically extend to survivorship with the potential to amplify many of the challenges experienced by cancer survivors.

### 5.1 Access to services

While patients in metropolitan centres might have physical access to services but find themselves thwarted by lack of awareness of these services or referral to them, patients and healthcare professionals in rural areas have relatively few services at their disposal.

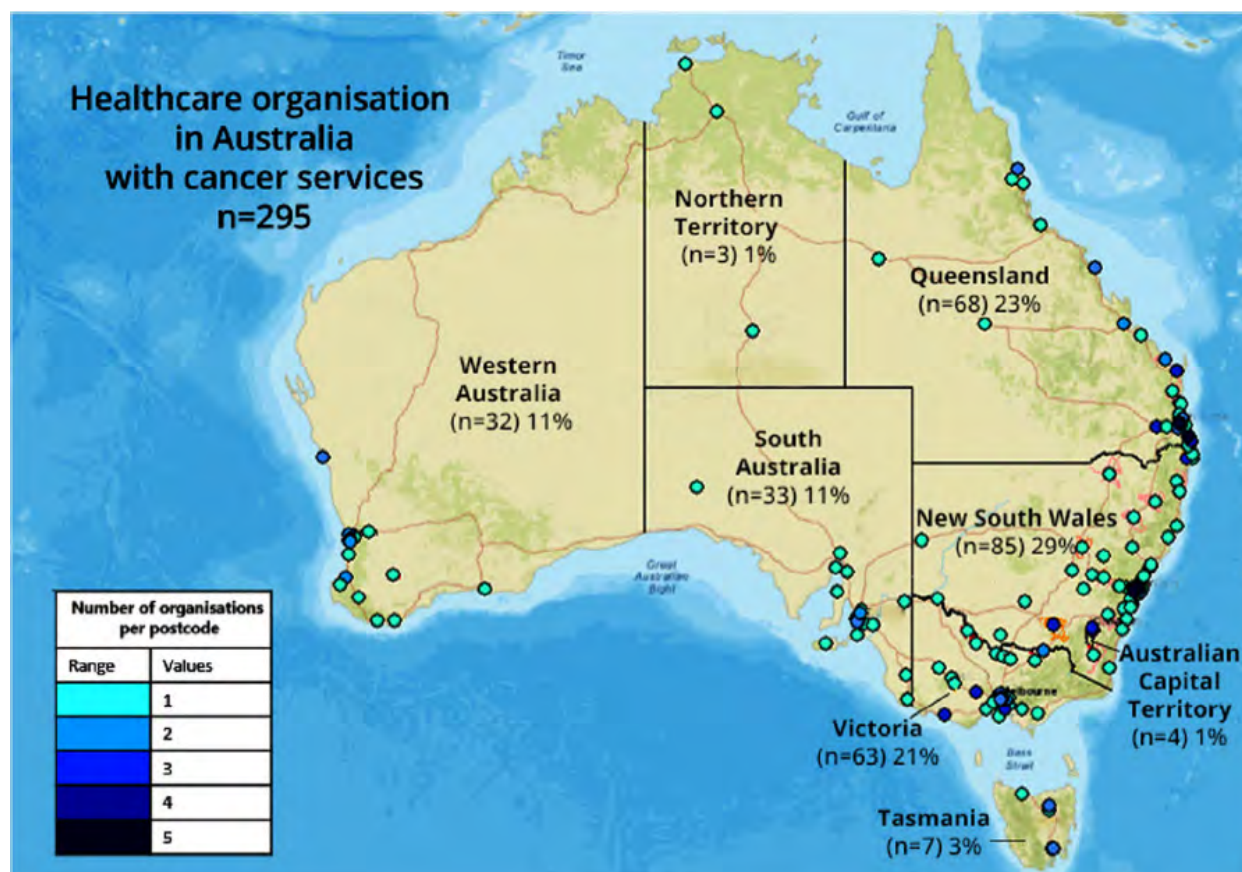
The vast majority of cancer survivorship services in Australia (including services required for ongoing disease surveillance) are concentrated in major cities and delivered in person so they simply cannot be accessed by those outside these areas. In a survey of 5,426 people with a history of cancer, nearly 50% of rural cancer survivors reported needing to travel more than 100km to access a health service, in contrast to 16% of urban survivors (48).

Even those patients who are able to travel to metropolitan centres to receive survivorship care and support report a relative lack of access to information about post-treatment pathways, confusion regarding which specialists they should see for medical follow-up and uncertainty about what post-treatment strategies they can employ to maximise quality of life (40). This might be in part because rural populations have a higher proportion of people with lower socioeconomic status and education levels (48).

Rural cancer survivors also report feeling isolated, fearful and disconnected from local services when they return home from urban centres. This is exacerbated by the perception that their local health services lack knowledge about cancer (40) and by medical workforce shortages in rural areas (49).

The geographic distribution of Indigenous Australians is such that Indigenous people comprise approximately 1% of the population in major cities but 15% and 49% of the population in remote and very remote areas respectively (50). In addition, the incidence of certain cancers, such as lung cancer, have been shown to be significantly higher amongst Indigenous Australians in outer regional and remote areas compared with their city counterparts (51). It follows that Aboriginal and Torres Strait Islander people are likely to be disproportionately impacted by a lack of access to survivorship services and support outside of Australia's metropolitan areas.

**Figure 2: Distribution of cancer services in Australia as identified by Hunter J. et al.**



29. Coverage of cancer services in Australia and providers' views on service gaps: findings from a national cross-sectional survey. Hunter J. s.l. : BMC Cancer, 2019, Vol. 19:570.

The geographic distribution of Indigenous Australians is such that Indigenous people comprise approximately 1% of the population in major cities but 15% and 49% of the population in remote and very remote areas respectively (51). In addition, the incidence of certain cancers, such as lung cancer, have been shown to be significantly higher amongst Indigenous Australians in outer regional and remote areas compared with their city counterparts (52). It follows that Aboriginal and Torres Strait Islander people are likely to be

disproportionately impacted by a lack of access to survivorship services and support outside of Australia's metropolitan areas.

## 5.2 Suitability of available survivorship support

It is important to consider the unique and specific needs of survivors living in rural areas and of vulnerable groups of survivors to ensure that available services can sufficiently meet their needs. For example, people living in rural areas might have different attitudes towards seeking help compared with their city counterparts. In a small community, people might be reluctant to discuss intimate psychosocial and financial issues with healthcare professionals who they are likely to know or meet socially (52). At the same time, rural communities might offer social support that is less available in metropolitan centres, and efforts are being made in some communities to connect survivors with groups that are not cancer-specific but can provide some support. For example, one participant in the consultation described the important role that organisations such as the Country Women's Association can play in supporting cancer survivors.

Meanwhile, in a review of the experiences of CALD minorities throughout the cancer continuum, Scanlon et al. report a number of inequities encountered by CALD patients (47). While some of these needs are consistent with those reported by non-CALD populations, others are indicative of a lack of support designed to specifically meet the needs of CALD minorities. These include, culturally or linguistically specific survivorship information and resources, appropriate caregiver information and care coordination that bridges any language barriers that may exist (47). Similarly, in a survey of 19 Aboriginal survivors, carers and healthcare workers, Meiklejohn et al. identified that improvements in culturally appropriate communication and support would help better meet the needs of Indigenous survivors in Australia (53).

## 5.3 Lack of health literacy

Insufficient health literacy exists across the board, but is a particularly acute problem for people with less education and for culturally and linguistically diverse populations such as Aboriginal and Torres Strait Islander groups.

In addition to being less able to advocate for access to services, cancer patients and survivors with poor health literacy may have more misconceptions about their disease and poorer communication with carers, with negative impacts on treatment provision, adherence, experience (e.g., anxiety) and outcomes (38) (54). Poor health communication therefore both exacerbates and is exacerbated by problems with health literacy. As with poor health literacy, poor communication can impact negatively on the quality of cancer care, on patients' perceptions of their health practitioners, on their experiences and quality of life and even on their out-of-pocket expenses (38). Poor communication can also lead patients to seek out unproven "alternative" interventions (54).

## 6. Key gaps in the Australian survivorship landscape

Biointelect's interviews and surveys with patient advocacy organisations and other stakeholders, together with a Roundtable discussion involving Australian thought leaders in the survivorship space, identified a number of key gaps across the Australian survivorship landscape. Although multiple gaps and concerns have been identified, these can broadly be grouped within the following three areas:



## 7. Innovative models of survivorship care

It is clear that existing models of survivorship care in Australia are failing to meet the needs of many survivors. Services and support are highly fragmented and vary between institutions and jurisdictions with many patients unable to access dedicated survivorship programs. Even where survivorship care may be available, the process of referring patients to appropriate services is made difficult by the lack of integration of survivorship support into existing care pathways. Additionally, existing models of care fail to adequately identify and address the unique needs of the individual – including in the case of vulnerable populations.

These shortfalls are likely to be compounded as cancer diagnosis and treatment options continue to evolve. As described in Section One, the number of people with a personal history of cancer is continuing to increase as improved cancer diagnosis and screening sees more patients diagnosed, while novel treatment options are contributing to an increase in the number of cancer survivors. With existing models of cancer follow-up consisting largely of in-person interaction with specialists and other healthcare professionals, this model is anticipated to become increasingly unsustainable.



**As a result, there is a need for new models of survivorship care which:**

Are consistent across Australia – providing equitable support for all survivors,  
Address the key gaps identified in the Australian survivorship landscape,  
Will be sustainable long term from.

Any new model of care should be supported by a strong evidence base and quantifiable metrics to ensure the needs of survivors and the healthcare system are effectively met.

As a result, there is a need to develop new models of survivorship care that not only have the capacity to address existing gaps in Australia's survivorship landscape but will also remain sustainable long term.

### 7.1 Virtual models of care

Virtual survivorship care models that utilise technological interventions have the potential to facilitate the provision of support, particularly for those patients who are considered at low risk of cancer recurrence or



ongoing complications (55). Virtual care models are likely to revolve around telemedicine and support provided by a range of healthcare professionals, including nurses and allied health professionals (55).

Digital interventions or tools may also be utilised as a component of virtual care. These include both digital therapeutics (DTx), which are evidence based medical interventions that have been evaluated in terms of their safety, efficacy and quality (56) and other digital tools including wellness and fitness apps that are broadly accessible but have not undergone rigorous testing or evaluation. Such interventions may facilitate care via smartphone or tablet applications and can also incorporate the use of other medical or wearable devices (56) (57).

Digital health interventions have been suggested as a means of encouraging health promoting behaviours amongst survivors such as increased physical activity, treatment adherence and quality of life. Various digital tools have also been explored as a means of managing side effects of maintenance treatment, such as insomnia, amongst cancer survivors (58). Digital technologies also provide an opportunity to effectively capture patient-reported outcomes that subsequently inform ongoing management (59).

A number of studies have demonstrated that virtual survivorship follow-up has the potential to deliver comparable patient outcomes to traditional methods of follow up, but at a lower cost (55). Importantly, virtual care has the potential to improve access to support for many Australians who may not live in close proximity to crucial services.

Despite the potential of virtual care, however, several barriers that still need to be overcome for these models to be effectively utilised, most notably (60) (40):

- The current lack of telehealth services within existing cancer survivorship services (<10%) and the focus of those telehealth services that do exist on the needs of urban cancer survivors
- Lack of ongoing and comprehensive MBS funding for telehealth services, and lack of integration of funding with other funding systems (e.g. funding for general practice consultations)
- Absence of supporting technologies (e.g. widely used and inter-operable electronic medical record systems)
- Failure of existing technologies to address the full range of issues that survivors face (e.g. issues surrounding return-to-work)
- Poor internet connections in rural areas
- Potential unsuitability for people who are unable to make use of technologies (e.g. people with certain physical or mental disabilities, or people who lack access to or are unfamiliar with computers)
- Lack of motivation for urban healthcare professionals to make use of telehealth and other digital technologies for a relatively small proportion of their patients
- Lack of trust on the part of healthcare professionals in telehealth services (e.g. the belief that they are not an effective means of delivering psychological support)

In the case of digital tools, barriers are largely systemic, with established regulatory and reimbursement pathways not designed to support the evaluation and funding of digital tools. The complicated nature of Australia's healthcare landscape and technical infrastructure may also hinder progress.

*“We don’t know who is going to pay for this [digital platform]. We can say we have this platform and patients love it and it increases quality of life but who will pay for it?” (digital therapeutic developer)*

The complexities of existing regulations regarding data privacy are also a potential barrier to telehealth and digital health technologies.

## 7.2 Appropriate funding mechanisms

Australia’s healthcare system operates on a largely fee-for-service (FFS) basis and as such, physician income is directly related to the volume and type of service provided. While FFS models of care are associated with advantages such as a high degree of flexibility for patients and physicians, they also incentivise an episodic approach to care, as opposed to wholistic consideration of patient outcomes. This may contribute to the challenge of managing cancer survivors and act as a barrier to the provision of care by nurses and other allied health providers.

As a result, developing innovative models of care which are supported by alternative funding mechanisms, such as bundled payments, may also help to better meet the needs of survivors. It is important to recognise, however, that all models of reimbursement create incentives and disincentives that impact differently on patient care. Robust economic modelling and analysis is, therefore, required to inform any changes to funding mechanisms for cancer survivorship services.

## 8. Recommendations

Biointellect's interviews and survey of patient advocacy organisations, together with a Roundtable discussion involving Australian thought leaders in the survivorship space identified a number of strategies that could help better meet the needs of Australian cancer survivors:



### 1. Policy reform

A strong, national policy for survivorship care would help address the widespread fragmentation seen in the provision of survivorship care at present and provide a sound platform for the development of innovative models of survivorship care. The current development of the Australian Cancer Plan provides an opportunity to link survivorship policy needs with wider cancer policy reform.



### 2. Develop innovative models of survivorship care

New models of survivorship care should be developed that address the existing gaps throughout the survivorship and cancer rehabilitation landscape and drive equitable outcomes for all Australians. These should take into consideration the rapid evolution of cancer diagnosis and treatment and subsequently the evolving needs of survivors. Care should include the effective identification, at an early stage, of survivor needs and the consistent referral to appropriate support. This needs to be embedded within existing referral pathways to ensure an effective and consistent approach for all patients.

Opportunities to help drive long term sustainability of survivorship care should also be evaluated to ensure health systems are able to support a growing number of survivors well into the future. This could include the utilisation of virtual models of care.

Any new model of care should be built on a sound evidence base and incorporate metrics that effectively quantify the quality of care provided. Appropriate metrics or key performance indicators could include patient reported outcome measures (PROMS) and other measurements of patient satisfaction. Development of metrics by leading Australian centres or service providers would help ensure relevance and uptake within existing programs and services.



### 3. Consider alternative funding models for survivorship care

Alternative funding models to FFS should be considered as a means of incentivising the provision of high-quality care over episodic interactions. Consideration should be given to a model whereby funding is provided to meet the needs of the individual and therefore depends on the type of support required. In concept, this could resemble the principle of the National Disability Insurance Scheme (NDIS). However, any new funding model for cancer survivorship should learn from the NDIS challenges and deficiencies.

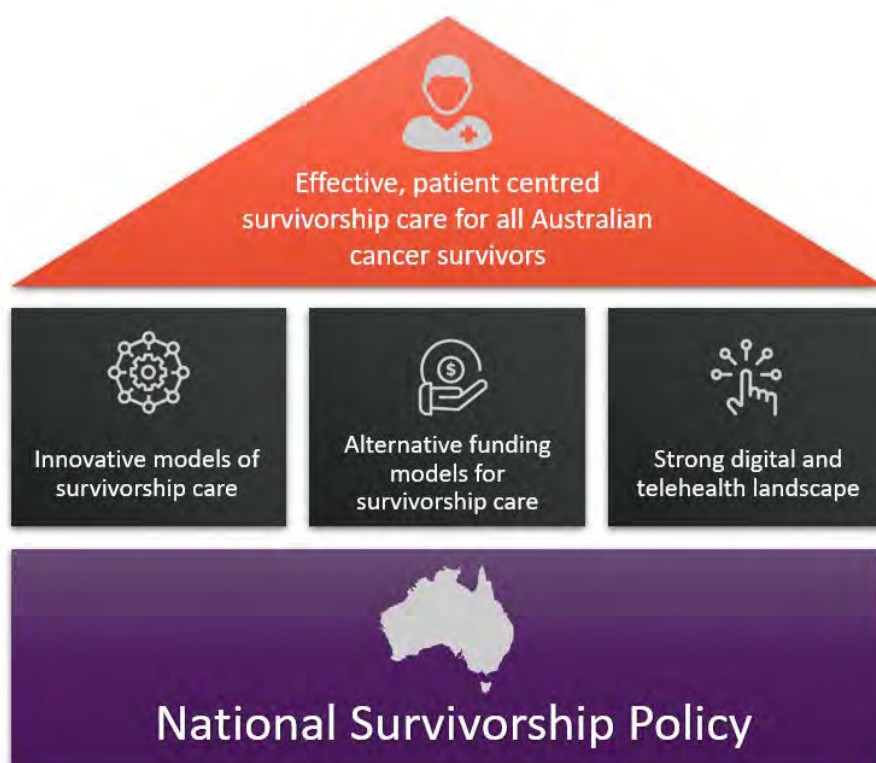


### 4. Strengthen Australia's telehealth and digital health infrastructure

Both telehealth and digital interventions are recognised as having significant potential to cost-effectively facilitate improved outcomes for survivors. The implementation of appropriate legislation and infrastructure to support these innovations is recommended to ensure they can be utilised to their full potential. This should include consideration of:

- MBS funding for telehealth services
- Fit for purpose regulatory and reimbursement pathways for digital therapeutics
- Appropriate legal frameworks to meet the expectations of consumers in relation to data privacy without creating a barrier to the collection and utilisation of real-world data

## Recommendations for improving survivorship care



## 9. Conclusions

Australia's cancer survivorship landscape is highly fragmented and existing models of care are failing to meet the needs of many cancer survivors. The key challenges currently experienced by survivors are likely to be compounded in the future as innovative medicines and diagnostics continue to increase the number of people living with a personal history of cancer or with cancer as a chronic disease. There is a need to reform the provision of survivorship care in Australia to ensure that the needs of all survivors can be met in a manner that is sustainable long term.

In order to achieve this goal, policy reform to support a nationwide approach to survivorship is needed. This should be considered a key component of any transformation in the survivorship space. New models of survivorship care with the potential to address existing shortfalls and remain sustainable long term should also be investigated. Meanwhile, alternative models of survivorship funding present an opportunity to drive improvements in the provision of high-quality survivorship care. Furthermore, there is a need to strengthen Australia's telehealth and digital health infrastructure to support the ongoing provision of sustainable survivorship care.



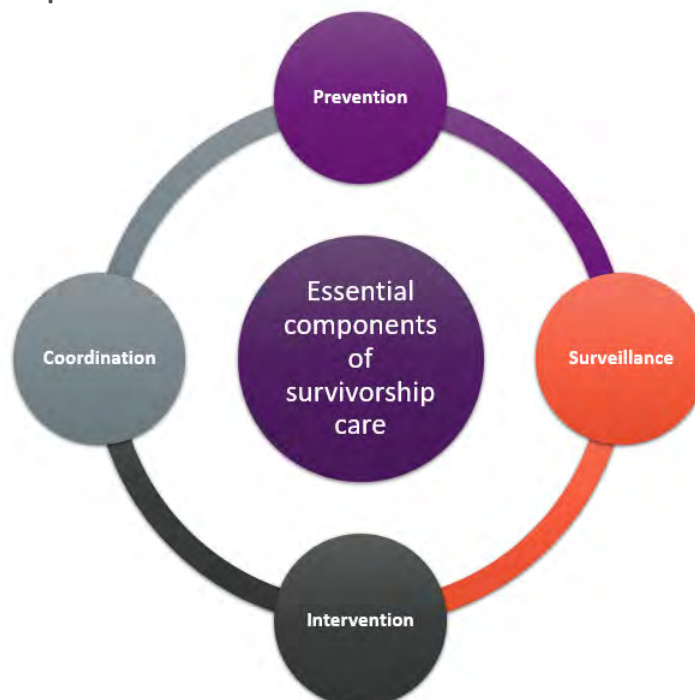


## 10. Appendix

### 10.1 Existing frameworks and models of Survivorship Care

In 2006, the United States IOM released a landmark report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, highlighting the unique needs and challenges faced by cancer survivors (25). The IOM report articulates four essential components of survivorship care: Prevention, surveillance, intervention and coordination.

**Figure 3: Essential Components of Survivorship Care, as outlined in IOM's Lost in Transition Report.**



25. Institute of Medicine and National Research Council. *From Cancer Patient to Cancer Survivor, Lost in Translation*. s.l. : The National Academies Press, 2006.



More generally, the IOM report emphasises the importance of:

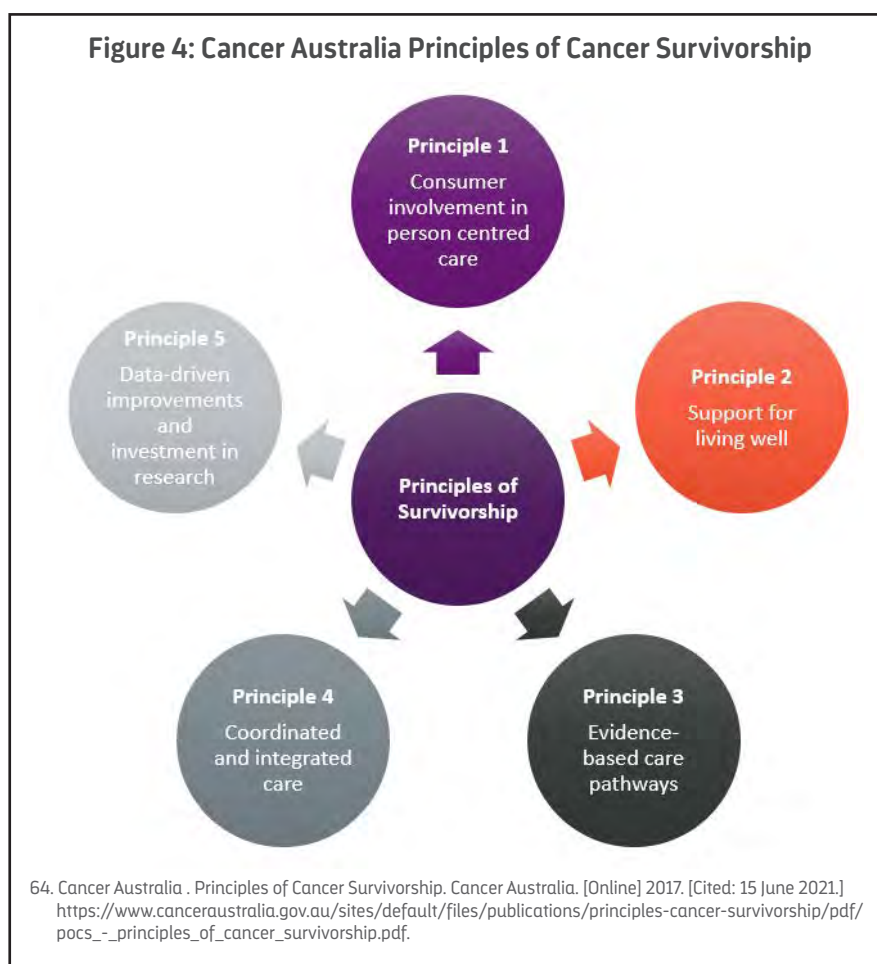
- Enabling individuals to participate in decision making,
- Engaging and motivating individuals to make positive health choices and
- Empowering them to seek information and support from relevant services.

The report also notes that consideration should be given to the survivor's stage in life and that those caring for survivors should address the issues that are most salient to them, such as fertility, peer-relations or connection with community services.

Globally, other influential frameworks have been derived from the IOM report, including the *National Action Plan for Cancer Survivorship: Advancing Public Health Strategies in the USA* (61) and *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020* (62) and the *National Cancer Survivorship Initiative (2008-2013) in the UK* (63).

Several Australian frameworks have been developed that articulate broad principles and strategies for survivorship care and support. Cancer Australia's *Principles of Cancer Survivorship* provides a national framework aimed at guiding policy, planning and health system responses (64). It articulates five principles supported by intended outcomes and underpinned by a focus on personalised care with opportunities for self-management.

The *COSA Model of Survivorship Care* (65) (28) describes three fundamental principles that should underpin models of survivorship care. These correspond with the essential components of survivorship care as defined in the *Lost in Transition* report. The COSA framework has a



strong focus on integration and continuity of care. As such, it emphasises that all relevant key stakeholders should be involved in the provision of survivorship care, including patients, caregivers, oncology teams and community providers. Like the IOM framework, the COSA framework emphasises higher order principles such as survivor-centredness. It also places importance on care being accessible and equitable.

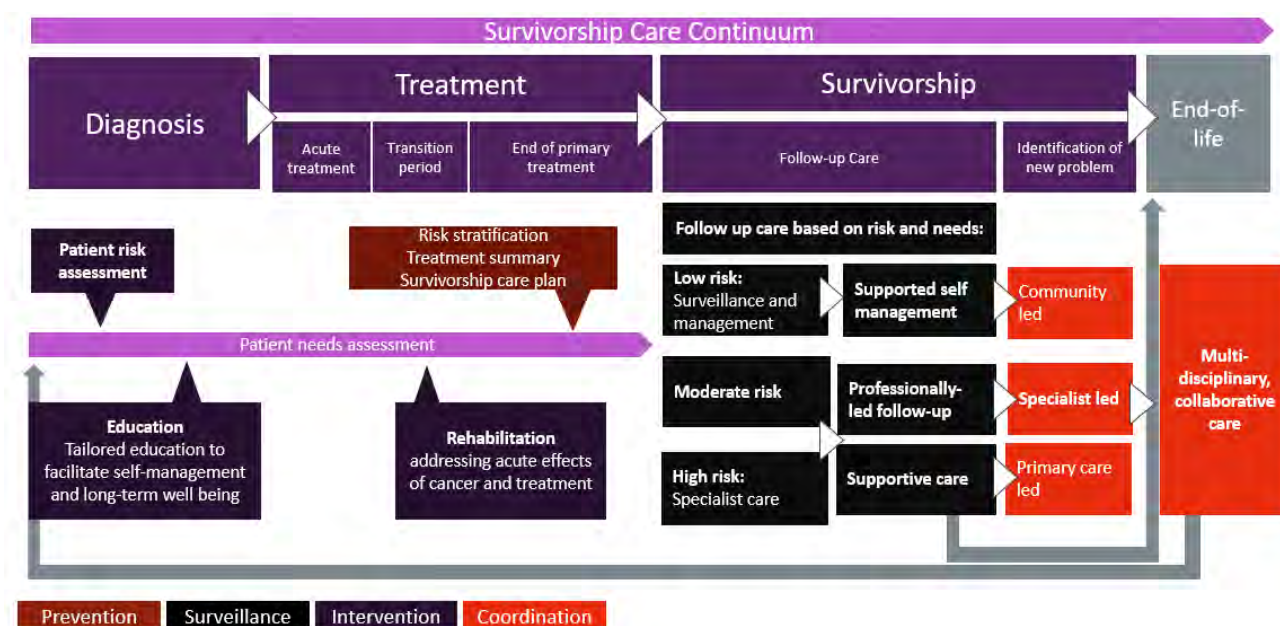
In addition to these national frameworks and policies, some states have implemented state-based guidelines (South Australia: Statewide Survivorship Framework; Victoria: Victorian Cancer Survivorship Program; Western Australia: WA Cancer plan (66)). These articulate how state-wide services should function in order to identify service needs; develop, coordinate, monitor and continuously improve care, and engage, inform and empower key stakeholders including cancer survivors and service providers.

Various models of survivorship care exist. The American Society of Clinical Oncology (ASCO) outlines a range of possible models, orientated around who provides care, and where this care is provided. It emphasises that each model has advantages and disadvantages and that the choice of model should be based on the population of survivors and their distinct needs as well as the availability of resources (67). ASCO also provide a guide for survivors, *ASCO Answers: Cancer Survivorship* (67).

Other models of survivorship care focus more on the continuum of care, noting when care needs to be provided and what needs to be provided at each stage. It is increasingly recognised that survivorship care needs to begin at the point of diagnosis, where risk assessments should be conducted, and education provided in order to ensure that patients understand how treatments may affect their life (8). As treatment reduces in intensity or becomes long-term, patients should be provided with education and any referrals necessary to support self-management and well-being as they move into the “survivorship” phase. When patients transition from acute care to follow-up care, a needs assessment should be conducted (including a risk assessment) and patients should be provided with a treatment summary and a survivorship care plan.

A model of care developed by COSA focuses on these longitudinal aspects of care (65):

**Figure 4: COSA Model of Survivorship Care.**



65. Clinical Oncology Society of Australia. Model of Survivorship Care, Critical Components of Cancer Survivorship Care in Australia, Position Statement. 2016.

Many models of survivorship care incorporate survivorship care plans (SCPs), yet these are often not routinely utilised. SCPs may be online or paper-based and generally include recommendations for education, supportive care, healthy lifestyle interventions and referrals to health care practitioners. They are intended to be regularly reviewed and updated by all healthcare practitioners involved in supporting the survivor, while also allowing the survivor to make their own notes. Well-designed SCPs facilitate planning, education, coordination and communication among all key stakeholders.

**Figure 5: Peter Mac Survivorship Care Plan**

22. Peter MacCallum Cancer Centre. Resources. Australian Cancer Survivorship Centre. [Online] <https://www.petermac.org/services/support-services/cancersurvivorship/survivors-and-carers/resources>.

## 10.2 Australian Survivorship Services

Some services focus on specific aspects of survivor care (e.g. education or exercise) while others, such as the Australian Survivorship Centre (ACSC) at the Peter MacCallum Cancer Institute in Melbourne, are more holistic (68). Some pharmaceutical companies have services in place, although in Australia these tend not to focus explicitly on survivorship care and support (69; 70; 71; 72; 73). Survivorship services and programs available in Australia include:

- Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre (68)
- Sydney Survivorship Centre, Concord Cancer Centre (74)
- Prince of Wales Hospital Cancer Survivorship Centre, Prince of Wales Hospital (76)
- Living well After Cancer, Cancer Council (76; 77; 78)

## 10.3 Abbreviations

|            |                                             |
|------------|---------------------------------------------|
| ACP        | Australian Cancer Plan                      |
| BMS        | Bristol Myers Squibb Australia              |
| ACSC       | Australian Cancer Survivorship Centre       |
| ASCO       | American Society of Clinical Oncology       |
| CAR T-cell | Chimeric antigen receptor T-cell therapies  |
| CHF        | Consumers Health Forum                      |
| CML        | Chronic myeloid leukemia                    |
| COSA       | Clinical Oncology Society of Australia      |
| CPIs       | Checkpoint inhibitors                       |
| CTLA-4     | Cytotoxic T-lymphocyte-associated antigen 4 |
| DTx        | Digital therapeutics                        |
| FFS        | Fee-for-service                             |
| IOM        | Institute of Medicine                       |
| MBS        | Medicare Benefits Schedule                  |
| PBS        | Pharmaceutical Benefits Scheme              |
| SCP        | Survivorship Care Plan                      |



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